



H.Res. 524 - Expressing the sense of the House of Representatives with respect to Diamond-Blackfan Anemia.

FLOOR SITUATION

H.Res. 524 is being considered on the floor under suspension of the rules and will require a two-thirds majority vote for passage. This legislation was introduced by Representative Carolyn McCarthy (D-NY) on June 27, 2007. This legislation was referred to the Committee on Energy and Commerce, but was not acted on.

H.Res. 524 is expected to be considered on the floor on October 15, 2007.

BACKGROUND

Diamond-Blackfan Anemia is a rare blood disorder in which the bone marrow does not make enough red blood cells to carry oxygen throughout the body. According to the Centers for Disease Control and Prevention (CDC), there are about 25 to 35 new cases of Diamond-Blackfan Anemia diagnosed in the United States and Canada each year.

Diamond-Blackfan Anemia is typically diagnosed within the first year of life.

SUMMARY

H.Res. 524 resolves that--

- the House of Representatives—
 - Recognizes that the identification of Diamond-Blackfan Anemia (in this resolution referred to as 'DBA') as the first human disorder with a ribosomal deficiency is a primary example of the importance of the Federal Government's continued support of DBA research, which may advance the understanding of the basic mechanisms that affect red cell production, identify connections of ribosomal function and cell cycle production, identify implications of cancer predisposition, and serve as an important model for understanding human development and the molecular basis for certain birth defects;
 - Recognizes that Federal support of comprehensive centers for rare disease patients enhances the ability for experienced doctors to provide the most complete care for each patient, leading to an increase in correct and early diagnosis and the most appropriate treatment for each patient;
 - Commends Schneider Children's Hospital for providing the first DBA Comprehensive Clinical Care Center for patients across the country, for developing

the DBA Patient Registry which has proven a robust surveillance tool to understand the epidemiology, biology, and treatment of DBA, and for proving a valuable resource for investigators at a national level, working to understand DBA's link to more prevalent disorders facing Americans; and

- Commends the Daniella Maria Arturi Foundation and the Diamond-Blackfan Anemia Foundation for their efforts to facilitate the successful collaboration among the National Institutes of Health and the Centers for Disease Control and Prevention to achieve a successful multidisciplinary approach between clinical and scientific DBA efforts with the goal of shortening the life cycle of success realized between the laboratory and applied patient care; and
- It is the sense of the House of Representatives that the Federal Government has a responsibility to--
- Encourage further efforts to clarify the natural history of DBA to--
 - (i) advance hematopoietic research in the area of bone marrow failure disorders;
 - (ii) develop a well-characterized database of patients linked to a cell and DNA repository to facilitate gene discovery;
 - (iii) understand the cellular and molecular biology of DBA;
 - (iv) understand the links to cancer and birth defects; and
 - (v) provide models for preclinical gene therapy trials;
 - Continue efforts to raise awareness and ease access to information about DBA among patient groups and the medical community to improve accuracy of diagnosis and identification of appropriate treatment options available;
 - Encourage research efforts that will advance the treatment options available to patients with DBA and seek a cure;
 - Encourage the National Institutes of Health to develop a cross-institutional research initiative to study ribosomal protein deficiencies in rare inherited disease, including DBA, among the relevant institute stakeholders interested in ribosome synthesis including--
 - (i) the National Heart, Lung, and Blood Institute;
 - (ii) the National Institute of Diabetes and Digestive and Kidney Diseases; and
 - (iii) the National Cancer Institute; and
 - Encourage the continued Federal support of the DBA Comprehensive Clinical Care Centers to further provide a definitive characterization of the patients with DBA, which will expand research and clinical care in order to help manage this rare illness, while also enabling hematologists, cancer researchers, geneticists, basic scientists, and others to continue to utilize the Center to enhance the study of this disease to better understand its links to many other problems facing Americans relating to blood cell formation, cancer predisposition, birth defects, and more.

STAFF CONTACT

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